

1-4-2017

# Promoting Family Resilience as a Population Health Strategy

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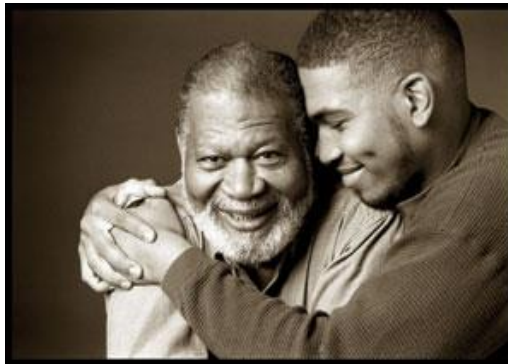
### Recommended Citation

Jacobs, Psy.D., Barry J., "Promoting Family Resilience as a Population Health Strategy" (2017).  
*Department of Family & Community Medicine Lectures, Presentations, Workshops*. Paper 154.  
<http://jdc.jefferson.edu/fmlectures/154>

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# PROMOTING FAMILY RESILIENCE AS A POPULATION HEALTH STRATEGY

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Barry J. Jacobs, Psy.D.

Crozer-Keystone Family Medicine Residency

Co-Author, AARP Meditations for Caregivers

# TODAY'S TALK



- Why family matters to population health
- Research from two movements
- Steps toward patient and family resilience
- Barriers to integrating family caregivers into healthcare
- Healthcare-based family caregiver support programs: Baylor Scott & White, Concord Hospital















# Why Family Matters (More Than Ever) in Healthcare

- Despite traditionally patient-centric American healthcare system, myriad factors -> emphasis on families
- Rapidly aging population (20% over 65 by 2030)
- Rising incidence of chronic illnesses, functional limitations
- Decreased hospital lengths of stay and emphasis on preventing bounce-backs
- **Families seen as one key to implementing outpatient treatment plans, decreasing hospital utilization and lowering costs**

# Two Movements



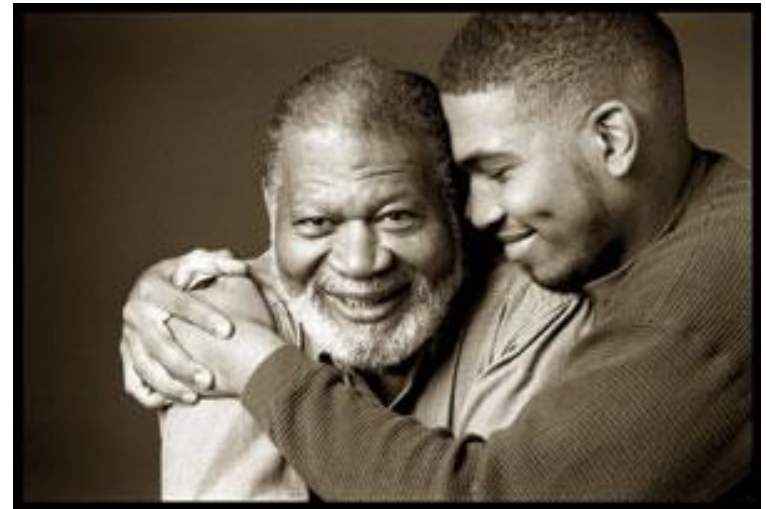
- **1) Family Systems Medicine**--bringing insights of family systems theory and family therapy to physical healthcare, research on families + health
- Don Bloch, MD: founder of journal (now Families, Systems & Health) in 1983; co-founder of CFHA
- *Family-Oriented Primary Care* (McDaniel et al, 1990, 2004)
- Medical family therapy (McDaniel, Hepworth, Doherty, 1992; Rolland, 1994; Wright et al, 1996)



- **2) Family caregiving**—multi-disciplinary **research** and practice over past 30 years, originally focused on dementia--e.g., Aneshensel et al, 1995, Gaugler & Kane, 2015
- Healthcare and legislative policy/consumer advocacy—e.g., Caregiver Action Network, **Mintz**, 1993; National Alliance for Caregiving, 1996, United Hospital Fund of New York's Families and Health project, **Levine**, "Next Step in Care"

# Family Caregiving in America

- 43 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2015)
- Numbers increasing because of demographics, medical advances





## US Caregiving (cont.)

- Heterogeneous group—e.g., ¼ Millennials
- Roth et al (2009): Results of epidemiological survey of 43,000 respondents:
  - 33% of caregivers reported no strain; 49% some strain; 18% a lot of strain
- **“Strains and gains”**

- **Schulz:** dementia caregiving associated with insomnia, depression, musculoskeletal problems, increased mortality



- **Roth:** caregiving associated with increased lifespan, enhanced sense of purpose

# Fragmented Care Teams

- Patchwork of healthcare and social service providers across multiple settings
- Poor communication
- PCP, neurologist, psychiatrist, neuropsychologist, psychotherapist, nursing, PT/OT, speech
- Home health aides
- Adult day care
- Disease-specific orgs.



# Family Caregivers' Healthcare Roles (Wolff, Jacobs, 2015)

- Attendant
- Administrator
- Companion
- Driver
- Navigator
- Technical Interpreter
- Patient Ombudsman
- Coach
- Advocate
- Case Manager
- Healthcare Provider





# Research on Impact of Family Functioning on Patients' Outcomes

Examples:

- Improved treatment retention adherence among HIV youth (Wiener, 2007)
- **Family presence improves quality of medical visits (Wolff, 2008, 2011)**
- Family involvement can improve patients' knowledge about diabetes (Kang, 2010)
- Caregiver availability lowers post-stroke costs (Roth, 2016)
- Telephonic caregiver support group **lowers costs** of care for veterans with dementia (Wray, 2010)

## Research (cont.)

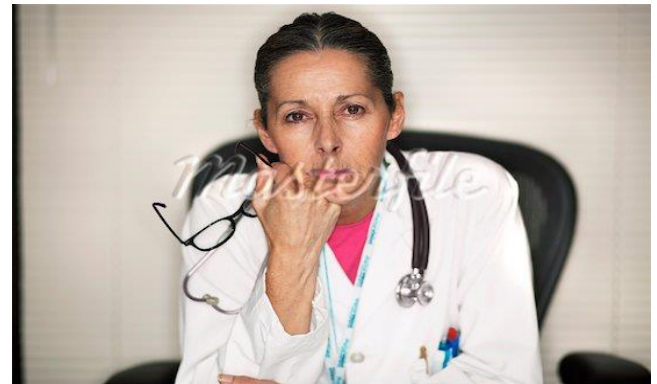
- Notable example: Mary Mittelman's NYU Caregiver Intervention—increases caregiver well-being, forestalls nursing home placement of Alzheimer's patients for nearly 2 years (2006)



- ***“A persistent tendency to equate families with trouble is evident in both the literature and practice of medicine.”—Levine & Zuckerman, Annals of Internal Medicine, 1999***

# Justifications for Patient-Centric Care

- *“Family caregiver involvement undermines patient autonomy and confidentiality”*
- *“It alters the quality of the patient-professional relationship”*
- *“Working with families takes additional time”*







- ***“I don’t want to get in the middle of conflict between the patient and family member. I don’t want any conflict with the family member.”***
- ***“The time I spend with patients’ family members is unreimbursed.”***

# Elements of Family-Centered Integrated Care

- Acknowledgement
- Communication
- Decision-Making Power
- Money
- Assessment
- Care management/coordination
- Training & Support
- Technology

# Acknowledgement



- Identification of family caregiver in patient's chart (Mintz)
- Recognition of dyadic nature of care:
- ***“We, the family Mintz, need clinicians and payers to view us as a single unit of care.”***

# Caregiver Advise, Record, Enable (CARE) Act

- Passed by 33 states:
- Requires identification of primary family caregiver in patient's hospital chart
- Family caregiver to be notified when patient is discharged
- Requires in-person instructions about medical tasks that family caregiver will provide for patient at home

# Caregiver Entry Field

## Dependency screen

Are you independent with all IADL functions?

i

Yes, independent

No, dependent

(These activities include shopping, transportation, laundry, light housework, light meal preparation, telephone, taking meds")

Social Support

Who could help you in case of emergency?

Phone number:

Caregiver name:

Caregiver phone number:

## Advance Directive

☐

Include Directive in Note

☐ Counseled regarding importance of Advance Directive Planning

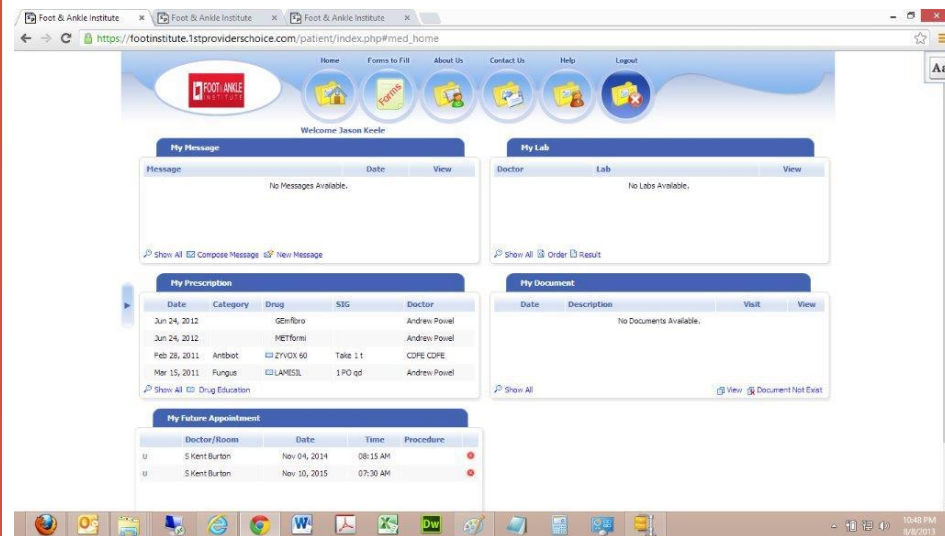
Last review of Advance Directive

Directives PAIN MANAGEMENT CONTRACT

MICROSYSTEM

# Communication

- Access to basic patient information through portals
- Access to providers' notes
- Ability to record observations
- Ability to comment on providers' notes





# Decision-Making Power



- Include patient and family goals in care plans
- Consider family caregivers as lay members of healthcare team
- “Shared decision-making”
- “Empowerment” (Feinberg)

# Money



- ***“Develop payment incentives for healthcare providers to support family caregivers’ involvement”*** (Levine)
- Should produce measurable change, including appropriate healthcare utilization, improved quality of life, etc.

# Assessment

- ***“Assessing and addressing both the individual’s and the family caregivers’ information, care, and support needs and their experience of care”*** (Feinberg)
- Willing and able to perform care tasks?



# Care Management/Coordination

- Family caregivers are acknowledged for the care management and coordination roles they already fulfill
- But caregivers may need additional help from care managers, especially during patients' transitions from one care setting to another
- E.g, Coleman, Naylor

# Training & Support

- Better preparation for family caregivers for performing complex medical tasks at home
- More support groups
- More online support services
- For pros: Retraining in HIPAA (Whiting)



# Technology

- Not just EMR portals
- Enhanced portals (e.g., VA Blue Button) with easy access, medication support systems, etc. (Whiting)
- Mobile technology (e.g., VA Family Caregiver Pilot)



Blue Button  
**Download  
My Data**



# Baylor Scott & White Health

- Focused on improving quality of care and decreasing utilization of dementia patients (Stevens & Thorud, 2015)
- Two programs based on incorporating REACH-II interventions into healthcare services and partnering with community social service agencies



## Baylor (cont.)



- **Family Caregiver Program:** identification of caregiving in EMR; calls from Dementia Care Specialist to provide education and support; followed for 6 months; referred to Central Texas Aging, Disability and Veterans Resource Center
- Results:
- Decreased caregiver burden and patient problem behaviors

# Baylor (cont.)

- **Community Living Program:**
- Individualized care plans that included caregiver supports
- \$750/month for homecare services
- Implementation of Care Transitions Intervention (Coleman)
- Results:
- Dementia patients had improved overall functioning and decreased hospital, ER and office utilization
- Caregivers had improved overall functioning and decreased ER visits and hospital admissions

# Concord Frail Elder Housecall Program

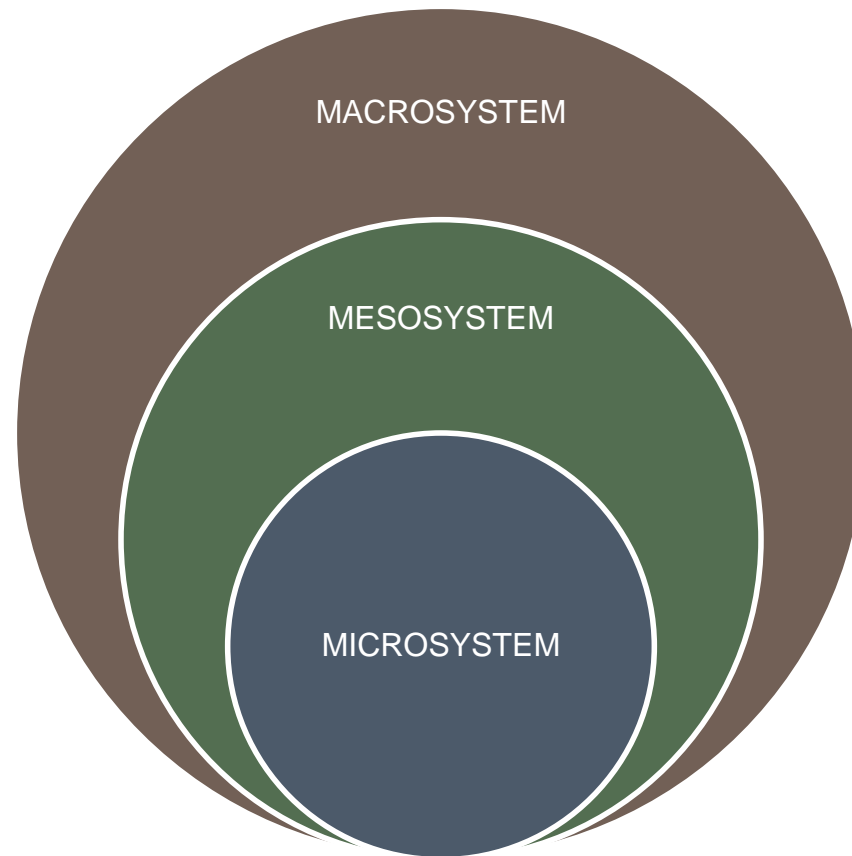
## **Purpose:**

Our system exists to provide home-based primary care to frail elders in the community, and teach geriatrics to family medicine residents.

## **Team:**

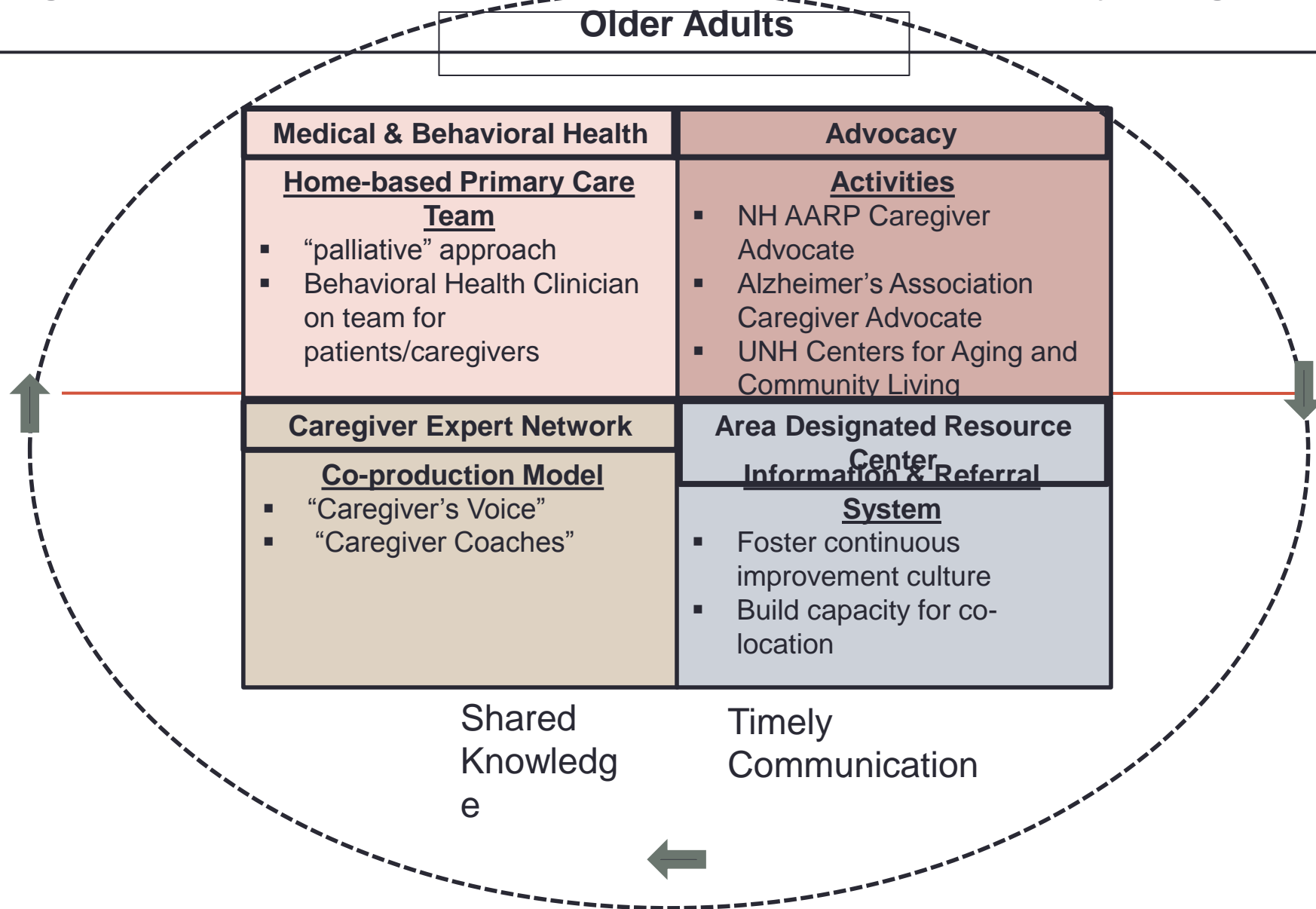
- Providers: Geriatrician MD, NP, PA-C
- Integrated Behavioral Health Clinician (Family Therapist)
- RN coordinators
- Family Medicine/Preventive Medicine Residents

# Systems Approach



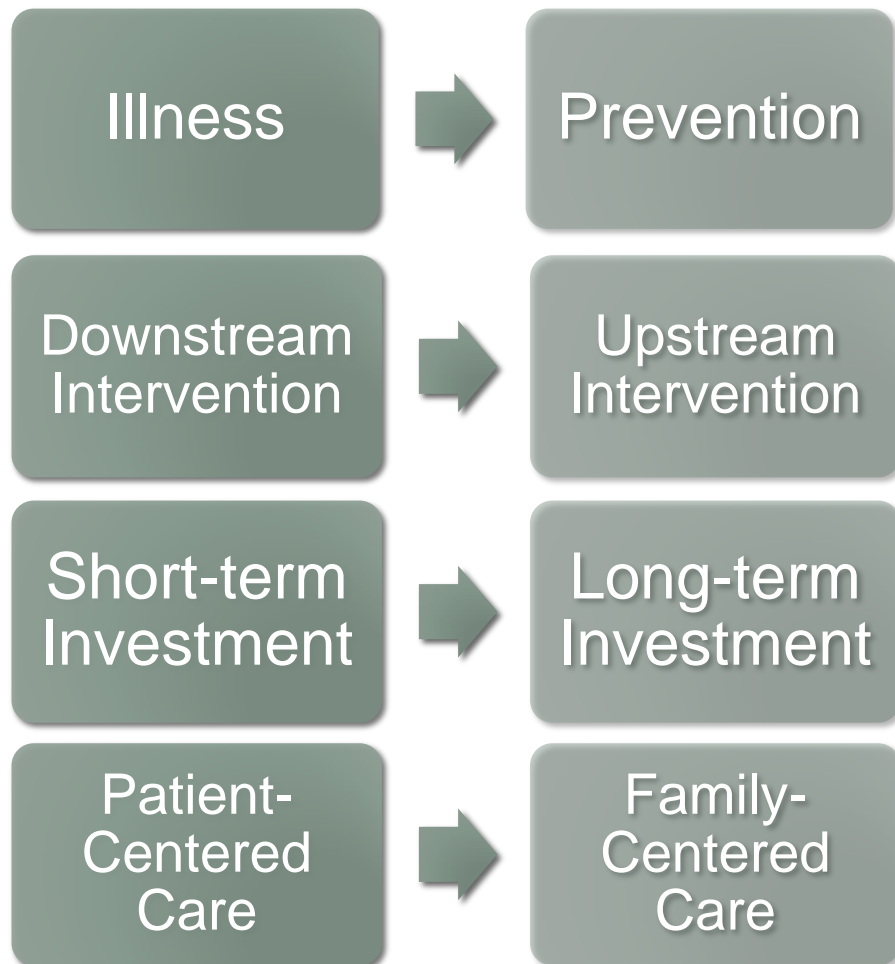
**Mission:** We partner with patients, families, and community-based organizations in building caregiver resilience.

# Agile, Population-Based Framework to Support Health of Family Caregivers of Older Adults





# Family-centered care is Population Health!



“Improved population health is unlikely without greater attention to the role of family caregivers, and the platform of population recognizes the full value of family caregivers...”

*- Alan Stevens (Founder, Family Caregiver Program at Baylor Scott & White Health)*

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